

Economic Impact on Families Caring for Children with Special Health Care Needs in New Hampshire: The Effect of Socioeconomic and Health-Related Factors

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Objectives: To describe the economic impact on families of caring for children with special health care needs (CSHCN), and to determine the relative contributions of socioeconomic and health-related factors to these impacts on families in the State of New Hampshire. **Methods:** Seven hundred and fifty families with CSHCN in New Hampshire were interviewed in the National Survey of Children with Special Health Needs. Among respondents with CSHCN, univariate and bivariate analyses were conducted to examine economic impact and independent factors (income, insurance type, and impact of condition). Multiple logistic and linear regression models were used to examine relationships between impact and independent factors, controlling for race/ethnicity. **Results:** Compared to typical children, CSHCN were more likely to have public insurance (12% and 21%, respectively) and less likely to live in higher income families (56% and 48%, respectively). Among CSHCN, nearly one-quarter were greatly affected by their condition, 31% had inadequate insurance, families of 21% had financial problems, parents of 27% had to cut work hours, and almost 15% needed professional care coordination. Adjusting for other factors in regression models, the impact of the condition was associated with all measures of impact, insurance type was associated with out-of-pocket costs, and income was associated with the total number of impacts. Parents of children who are usually or always affected by their conditions were 14 times more likely than those who are never affected to need care coordination. **Conclusion:** A family's need for support services, and particularly for care coordination, may depend less on the family's means than on the impact of their child's condition.

KEY WORDS: children with special health care needs; family burden; economic burden; economic impact.

INTRODUCTION

The population of children with special health care needs (CSHCN) is defined by the need for health services beyond those required by typical children (1). Children with chronic health conditions require a wide range of ser-

vices, from primary and specialty medical care to therapies, equipment, assistive devices, and prescription medications (2). Access to these services requires insurance that provides adequate benefit coverage and provider networks, and co-payment requirements that do not burden families financially (3).

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In addition to their children's need for health and support services, the effects on a family of caring for a child with special health care needs are wide-ranging, including financial impact (4, 5), employment sacrifices (6, 7), and emotional stress (8, 9). To help them cope with these impacts, families of CSHCN often require support services, including care coordination, respite care, and family counseling (10). Moreover, everyday expenses may be greater for CSHCN; one study found that parents of CSHCN in Britain spent up to four times as much on everyday items as did other families (11). CSHCN are also more likely to live in low-income families (12), whose support needs may exceed their resources to address them.

Variation in access to and use of services by CSHCN and their families is primarily attributed to socioeconomic factors. Health insurance is a major influence on the use of services by CSHCN; publicly insured CSHCN have been found to be more likely to use services, particularly support services, than either those with private insurance or those without insurance, and uninsured CSHCN are less likely to have a usual source of care and to receive specialty care, dental care, mental health services and prescription medications (2, 3, 13, 14). Other socioeconomic factors are important as well. Children in low-income families, minorities, and those whose mothers have low levels of education are less likely to receive care (13, 15).

In this study, we hypothesize that socioeconomic characteristics influence the economic impact of CSHCN on families as well. While research has focused on the correlates of children's access to care, few studies have examined the characteristics that influence the impact on and needs experienced by their families. Because of the range of needs experienced by CSHCN and their families and the differential burden borne by families of differing socioeconomic backgrounds, it is important to identify the factors that affect the levels of economic impact experienced by families of CSHCN. This issue is particularly salient in New Hampshire, where efforts are underway to revise eligibility for Medicaid and the Home Care for Children with Severe Disabilities program (HC-CSD) commonly referred to as Katie Beckett. Title V patient services dollars may be requested to assist these families.

The National Survey of Children with Special Health Care Needs (NSCSHCN) provides an opportunity to examine the factors that influence the effect of having a child with special health care needs

on families on both the state and national levels. The New Hampshire Department of Health and Human Services used the state-level survey to examine the relative influence of socioeconomic and health-related factors on the impact of having a child with special health care needs on families in New Hampshire.

METHODS

Study Population

The study analyzed the New Hampshire component of the NSCSHCN by merging records from the screener, insurance and interview files. Respondents to the NSCSHCN were excluded if they resided outside the State of New Hampshire, yielding an analytical sample of 750 CSHCN and 2,975 children without special health care needs. Children with and without special health care needs were compared with respect to family income and type of health insurance. The remaining analysis of the impact of family income, insurance type and impact of condition on family burdens was restricted to a sample of only CSHCN and their families.

Measures

Independent variables included family income relative to the Federal Poverty Level (FPL), type of health insurance, and perceived impact of the child's condition on their ability to function. Family income responses were collapsed into three categories: below 100% FPL; 100–299% FPL; and above 300% FPL. Health insurance status was categorized as public (through Medicaid, the State's Child Health Insurance Program [CHIP], Title V, the Indian Health Service, and/or other public insurance), private (including military, other private insurance, and/or single type of insurance plan), a mixture of both private and public, or uninsured. The impact of the child's condition measure was derived by combining responses from two variables: 1) the amount of time during the previous 12 months that the child was affected by the condition, and 2) the impact of the child's condition on his or her ability to function.

Outcome measures included measures of economic impact, adequacy of health insurance, and the need for professional care coordination. Measures

of economic impact included whether or not a family member stopped working to care for the child, whether a parent had reduced work hours to care for the child, whether the family needed additional income to meet the child's medical expenses, and whether the family experienced financial problems. In addition to analyzing these dichotomous variables separately, they were combined into a quasi-continuous measure of economic impact by counting the number of these impacts each family experienced. The measure of professional care coordination was derived from a question regarding the need for professional care coordination at any point during the previous 12 months.

Adequacy of health insurance was measured through three questions: whether their insurance plan offers benefits and covers services that meet the child's needs; whether the costs not covered by the plan are reasonable; and whether the plan allows the child to see the health care providers he or she needs. Those who answered "usually" or "always" to all three of these questions were considered to have adequate health insurance coverage.

Finally, a quasi-continuous cost index was created based on parents' reports of their out-of-pocket expenditures for the child's medical care in the previous year. Because respondents were asked to choose among ranges of expenditures, it was not possible to calculate mean out-of-pocket expense or to compare these expenses to family income. Therefore, a cost index was developed that assigns values to the various ranges: 0 = \$0; 1 = less than \$250; 2 = \$250 to \$500; 3 = \$501 to \$1,000; 4 = \$1,001 to \$5,000; and 5 = more than \$5,000.

Statistical Methods

Data management tasks, including the recoding of variables, were accomplished using Statistical Analysis Software (SAS) version 8.2 (SAS Institute Inc., Cary, NC). All univariate, bivariate, multiple logistic regression, and multiple linear regression analyses were conducted using Survey Data Analysis (SUDAAN) version 8.0 (RTI International, Research Triangle Park, NC) employing the CROSSTABS, RLOGIST and REGRESS procedures. SUDAAN takes into account the complex sampling design of the NSCSHCN to estimate weighted percentages, standard errors and confidence intervals.

RESULTS

Table I shows the percent distribution of income and type of health insurance for CSHCN and children without special health care needs in New Hampshire. The two populations differed significantly in both income distribution and type of insurance. Compared to typical children, CSHCN were more likely to have public insurance (either alone or in combination with private coverage), and less likely to live in higher-income families (300% FPL or more) and to be privately insured.

Univariate distributions of the indicators of economic impact on families with CSHCN are displayed in Table II. Nearly one-quarter of children were affected in their activities usually, always, or a great deal. Nearly one-third of insured families

Table I. Income Level and Type of Insurance, by CSHCN Status in New Hampshire

	Children with Special Health Care Needs (<i>n</i> = 750; Weighted <i>N</i> = 47,059)			Children without Special Health Care Needs (<i>n</i> = 2,975; Weighted <i>N</i> = 265,424)			<i>p</i> **
	<i>N</i>	Weighted <i>N</i>	%* (S.E.)	<i>n</i>	Weighted <i>N</i>	%* (S.E.)	
Income							<.05
<100% FPL	61	5,255	12.4 (2.0)	147	16,662	7.2 (0.7)	
100–299% FPL	267	16,731	39.4 (2.4)	918	84,930	36.8 (1.2)	
300% FPL +	346	20,484	48.2 (2.5)	1,496	129,366	56.0 (1.2)	
Type of insurance							
Private	542	30,963	65.8 (2.4)	2,430	207,033	78.0 (1.0)	<.001
Public	113	10,087	21.4 (2.3)	288	30,524	11.5 (0.8)	
Both	39	2,794	6.8 (1.0)	96	9,974	3.8 (0.5)	
Uninsured	56	3,215	5.9 (1.2)	161	17,893	6.7 (0.7)	

Source: New Hampshire component of National Survey of CSHCN.

*Weighted percent. Due to rounding, percents may not add to exactly 100%.

**The *p*-value for the Pearson chi-square statistic.

Table II. Indicators of Impact of CSHCN in New Hampshire

	<i>n</i>	Weighted <i>N</i>	%* (S.E)
Impact of condition on child's ability to function			
Usually/always or a great deal	147	11,501	24.6 (2.3)
Sometimes	288	16,868	36.1 (2.2)
Never	311	18,428	39.4 (2.2)
Family member stopped working to care for child			
Yes	71	4,713	10.1 (1.6)
No	675	41,977	89.9 (1.6)
Needed additional income for child's medical expenses			
Yes	91	5,652	12.1 (1.6)
No	655	40,991	87.9 (1.6)
Adequacy of health insurance**			
Adequate	500	30,480	68.9 (2.3)
Inadequate	211	13,784	31.1 (2.3)
Financial problems			
Yes	136	9,593	20.6 (2.1)
No	610	37,044	79.4 (2.1)
Cut work hours			
Yes	181	12,544	26.9 (2.3)
No	565	34,148	73.1 (2.3)
Needed professional care coordination			
Yes	98	6,978	14.8 (1.8)
No	652	40,081	85.2 (1.8)

Source: New Hampshire component of National Survey of CSHCN.

*Weighted percent. Due to rounding, percents may not add to exactly 100%.

**Among those with known type of health insurance.

with CSHCN reported inadequate insurance; 20 % of families reported financial problems; 27 % had to cut their work hours to take care of their child and 10 percent stopped working altogether; and 12 % reported needing additional income for the child's medical expenses. Nearly 15 percent of families reported that they needed professional care coordination.

Table III displays the bivariate analysis of these measures of economic impact by income level, insurance type and impact of the child's condition. Income was significantly associated with all of the measures of impact except need for care coordination; poor or low-income families with CSHCN were more likely than families with CSHCN with incomes above 300% FPL to report inadequate insurance, financial problems, need for additional income, cutting work hours, or stopping working. Type of insurance was less consistently associated with the impact measures; insurance type was significantly associated only with financial problems (highest among those with both public and private insurance and the uninsured) and cutting work hours.

The impact of the condition on the child's functional ability was significantly associated with all of the outcome measures. The parents of more than half of children who were affected always, usually, or a great deal reported inadequate insurance or cutting work hours; 40% had financial problems; 22% needed additional income; 19% stopped working; and 32% needed professional care coordination.

Relationships between dichotomous outcomes of economic impact (inadequacy of insurance, financial problems, need for additional income, reduction in the number of work hours, cessation of work, and need for professional care coordination) were assessed utilizing multiple logistic regression, controlling for race/ethnicity and other independent variables, the results of which are presented in Table IV. The impact of the child's condition on his or her functional ability was most strongly predictive of the impact on the family. Parents of children who were affected usually, always, or a great deal were strongly associated with having inadequate insurance, financial problems, cutting back work hours, needing additional income than families of children who were never affected in their activities. They also had a greater likelihood of needing professional care coordination.

Family income was significantly associated only with measures of financial impact; not surprisingly, the odds of reporting financial problems or a need for additional income among those in poverty were four to five times greater compared to families with incomes over 300% of poverty. After controlling for the other independent variables, insurance type was not significantly associated with any of the outcome measures.

Table V shows the results of multiple linear regression analysis of two quasi-continuous variables: indices of out-of-pocket expenditures and the number of economic impacts reported by parents of CSHCN. After controlling for race/ethnicity and independent variables in the model, privately-insured and uninsured CSHCN had mean index scores approaching 2, meaning they were more likely to spend at least \$250–\$500, while those with public insurance alone or in combination with private insurance had scores under 1, meaning they were more likely to have spent less than \$250. Similarly, families of children affected usually, always, or a great deal by their conditions had a mean index of 2.15, while those affected less often had scores under 2. There was no significant relationship between income and

Table III. Bivariate Analysis of Economic Impact on Families of CSHCN by Socioeconomic Characteristics and Impact of Child's Condition

	Income				Insurance type				Impact of condition				
	<100% FPL	100-200% FPL	300% FPL+	p**	Private	Public	Both	None	p**	Usually/Always/ Great			p**
										Great	Some-times	Never	
Inadequate insurance													
n	23	76	82	<.05	156	38	17	NA	NS	64	79	66	<.001
Weighted N	2,356	4,804	4,428		8,943	3,944	898	NA		5,305	4,981	3,316	
%* (S.E.)	47.0% (9.5)	31.0% (3.7)	22.9% (2.7)		28.9% (2.4)	39.1% (6.2)	27.9% (6.8)			50.6% (5.8)	31.5% (3.6)	18.7% (2.4)	
Financial problems				<.001					<.01				<.001
n	20	71	27		76	30	18	12		52	64	19	
Weighted N	1,901	4,810	1,791		4,357	3,156	1,130	950		4,702	3,833	1,008	
%* (S.E.)	36.2% (9.4)	28.8% (3.6)	8.8% (2.3)		14.2% (2.0)	31.7% (6.3)	35.2% (7.5)	34.3% (11.0)		40.9% (5.7)	23.0% (3.2)	5.5% (1.4)	
Need additional income				<.01					NS				<.001
n	13	43	24		57	13	9	12		33	45	12	
Weighted N	1,114	2,770	1,231		2,957	1,445	591	660		2,579	2,390	633	
%* (S.E.)	21.2% (7.9)	16.7% (2.9)	6.0% (1.4)		9.6% (1.5)	14.6% (5.0)	18.4% (6.4)	23.6% (7.7)		22.4% (4.8)	14.4% (2.4)	3.4% (1.1)	
Cut Work Hours				<.05					<.01				<.001
n	18	74	64		112	35	23	11		69	77	34	
Weighted N	2,023	5,022	3,942		6,442	3,730	1,500	872		6,029	4,675	1,789	
%* (S.E.)	38.5% (9.4)	30.1% (3.7)	19.3% (2.9)		21.0% (2.3)	37.5% (6.4)	46.7% (7.7)	31.2% (11.0)		52.4% (5.5)	28.0% (3.6)	9.7% (1.8)	
Family member stopped working				<.05					NS				<.001
n	15	26	19		39	15	10	7		30	28	12	
Weighted N	1,509	1,609	1,012		2,172	1,609	582	349		2,220	1,806	637	
%* (S.E.)	28.7% (9.0)	10.1% (2.5)	4.9% (1.2)		7.1% (1.4)	16.2% (5.4)	18.1% (5.9)	12.5% (6.1)		19.3% (4.7)	10.8% (2.6)	3.5% (1.1)	
Need professional care				NS					NS				<.001
care coordinator													
n	8	39	44		56	21	15	6		41	48	9	
Weighted N	930	2,861	2,597		3,654	2,174	809	341		3,727	2,654	597	
%* (S.E.)	17.7% (8.1)	17.1% (3.2)	12.7% (2.1)		11.8% (1.9)	21.6% (5.5)	25.2% (6.2)	12.2% (6.1)		32.4% (5.4)	15.7% (2.5)	3.25% (1.3)	

NS: not significant NA: not applicable. Source: New Hampshire component of National Survey of CSHCN.

*Weighted percent. Due to rounding, percents may not add to exactly 100%.

**The p-value for the Pearson chi-square statistic.

Table IV. Multiple Logistic Regression Analysis of Economic Impact on Families of CSHCN by Socioeconomic Characteristics and Impact of Child's Condition

	Income ^a				Insurance Type ^a				Impact of condition ^a				
	300% FPL+	100–299% FPL	<100% FPL	p**	Private	Public	Both	None	p**	Never	Some-times	Usually/Always/ Great	p**
Inadequate Insurance ^b (R ² = 0.102)													
AOR	1	1.33	2.28	NS	1	0.92	0.61	NA	NS	1	1.91	4.24	<.001
95% CI		(0.82–2.15)	(0.90–5.74)			(0.47–1.83)	(0.26–1.43)	NA			(1.17–3.13)	(2.32–7.74)	
Financial Problems ^b (R ² = 0.183)													
AOR	1	3.63	3.79	<.01	1	1.31	1.88	2.33	NS	1	4.72	8.97	<.001
95% CI		(1.81–7.25)	(1.34–10.67)			(0.61–2.79)	(0.76–4.62)	(0.57–9.59)			(2.26–9.84)	(4.12–19.50)	
Need Additional Income ^b (R ² = 0.106)													
AOR	1	3.15	5.13	<.001	1	0.55	0.98	1.92	NS	1	4.25	7.5	<.001
95% CI		(1.76–7.00)	(1.62–16.17)			(0.20–1.46)	(0.31–3.09)	(0.76–4.86)			(1.75–10.34)	(2.81–20.02)	
Cut Work Hours ^b (R ² = 0.153)													
AOR	1	1.25	1.18	NS	1	1.44	2.36	1.27	NS	1	3.39	8.82	<.001
95% CI		(0.72–2.17)	(0.44–3.22)			(0.71–2.92)	(0.98–5.67)	(0.32–4.99)			(1.88–6.11)	(4.59–16.94)	
Family Member Stopped Working ^b (R ² = 0.093)													
AOR	1	1.44	4.61	<.01	1	1.06	1.5	1	NS	1	3.86	5.38	<.01
95% CI		(0.65–3.21)	(1.43–14.88)			(0.43–2.63)	(0.46–4.96)	(0.26–3.81)			(1.48–10.08)	(1.98–14.63)	
Professional Care Coordination Needed ^b (R ² = 0.120)													
AOR	1	0.78	0.37	NS	1	2.52	1.95	0.75	NS	1	5.49	14.19	<.001
95% CI		(0.41–1.49)	(0.11–1.27)			(1.05–6.06)	(0.78–4.90)	(0.21–2.63)			(2.12–14.25)	(5.18–38.85)	

Note. AOR: Adjusted odds ratio. CI: Confidence interval. NA: Not Applicable. NS: Not significant. New Hampshire component of National Survey of CSHCN.

*Model controls for race/ethnicity, which is not shown.

**The p-value for the F-statistic based on the Wald chi-square.

^aIndependent Variable

^bDependent Variable

Table V. Multiple Linear Regression Analysis* of Cost Index and Impact Score by Socioeconomic Characteristics and Impact of Child's Condition

	Income ^a			Insurance Type ^a				Impact of condition ^a		
	<100% FPL	100-299% FPL	300% FPL+	Private	Public	Both	None	Usually/Always/ Great	Some-times	Never
				<i>p</i> ^{****}						<i>p</i> ^{****}
Cost Index ^{b,**} (<i>R</i> ² = 0.191)										
LS Means	1.76	1.6	1.62	NS	1.9	0.96	0.76	1.99	2.15	1.67
SE	(0.24)	(0.08)	(0.09)		(0.06)	(0.17)	(0.18)	(0.37)	(0.15)	(0.07)
Economic Impact Score ^{b,****} (<i>R</i> ² = 0.223)										
LS Means	1.04	0.79	0.47	<0.01	0.63	0.65	0.94	0.88	1.22	0.73
SE	(0.24)	(0.08)	(0.07)		(0.06)	(0.15)	(0.22)	(0.3)	(0.15)	(0.05)

Note. SE: Standard error. NS: Not significant. New Hampshire component of National Survey of CSHCN.

Independent Variable.

^bDependent Variable; LS = Least squared.

*Model controls for race/ethnicity, which is not shown.

***Index ranges from 0 to 5 (0 = \$0; 1 = less than \$250; 2 = \$250-\$500; 3 = \$501-\$1000; 4 = \$1001-\$5000; and 5 = more than \$5000).

Score of number of economic impacts ranges from 0 to 4. Economic impacts include reporting financial problems, need for additional income, reduction in work hours to care for CSHCN, and a family member ceasing work to care for CSHCN.

*****The p -value for the F -statistic based on the Wald chi-square.

expenditures independent of the association with insurance type.

The analysis of impact score presents the mean number of economic impacts reported by families in each category. Insurance type was not significantly associated with economic impact, but families in poverty were more likely to report more than one impact (mean = 1.04) than those with higher incomes, and families of children affected usually, always, or a great deal had a mean score of 1.22, compared to scores of less than 1 for families of children less severely affected.

DISCUSSION

Socioeconomic variables, such as income and insurance status, are known to be associated with access to health services for all children, including children with special health care needs. Indeed, families of CSHCN have lower incomes than families of typical children, and are more likely to have public health insurance. However, socioeconomic variables appear to have less influence on the specific effects of having a child with special needs on families, including financial strain, inadequate insurance, time commitments, and need for assistance in coordinating the child's care. Much more important is the degree of impact that the child's condition has on his or her activities; parents of children with greater levels of functional impairment are much more likely to report financial and time impacts than parents of children less consistently affected by their conditions.

Most striking is the greater level of need for professional care coordination services reported by parents of children who are usually or always affected by their conditions, a need reported 14 times more often by these parents than parents of children who are never affected, a finding with clear implications for policy and program planning. Care coordination services for families of CSHCN have been an important component of most state Title V programs for decades (16). Needs assessments continue to validate that care coordination services are a priority for families (17). It is reasonable to assume that the process of arranging and integrating the delivery of health and related services across providers and several service systems is most complex when the child is most severely affected by illness or disability. As Title V programs and other community-based services make decisions regarding allocation of resources, the New Hampshire findings suggest that

primary consideration should be given to providing professional care coordination to families whose children have the most significant health problems. To facilitate decision-making and strategic planning, it may be helpful to assess complexity and the need for care coordination using a tool like the Tier Levels for Health Care and Family Functioning developed by the Idaho Children's Special Health Program (18). This approach is currently being piloted by the New Hampshire Title V program.

These findings have significant implications for the design and implementation of systems of support services for CSHCN and their families. These findings indicate that a subset of the population of CSHCN has a greater need for support services, and that this population is defined not by income but by functional impact. Thus, while the MCHB's broad definition of CSHCN is useful for some purposes, it may not necessarily define the population in greatest need of support. Rather, subcategories within the broad definition may be needed to define eligibility for levels and types of interventions that are tailored to children's level of need. This approach would mirror that of the HC-CSD option under Medicaid, which provides for Medicaid eligibility for home-based services for all children needing an institutional level of care, regardless of the parents' income, rather than the Supplemental Security Income (SSI) program, which bases eligibility on family income as well as severity of a disability. In New Hampshire efforts are underway to further assess the needs of the HC-CSD population in order to better plan services for these children and families.

While this analysis is based on a representative sample, it does have some limitations. Because New Hampshire is a small, largely rural state with a relatively homogeneous population, we did not find variation that might be present in other states. In addition, while the sample size was large enough for meaningful analysis, the size of some cells was limited. Finally, parents' assessments of their children's functional abilities and limitations are subjective and may vary.

This analysis also reveals the need for additional research on the economic impact experienced by families of CSHCN and the factors that influence them. For example, while the impact of a child's condition is clearly the most significant factor of those analyzed here, this variable only explains 22% of the variation in the number of impacts families experience. For the linear regression models shown here, between 19 and 23% of the variance was accounted

for in the association between the independent and outcome variables (R^2 values for cost (0.191) and burden (0.223)). Further research is needed on the other factors that might influence this variation, e.g., specific family variables or situations.

Services for CSHCN and their families are typically directed to low-income or uninsured populations. However, as this study shows, a family's need for support services, and particularly for care coordination, may depend less on their financial means than on the impact of their child's condition, and alternative eligibility criteria may be needed.

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